

### Pathways to death: the co-occurrence of physical and mental health in the last years of life

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### *Descriptive Finding*

## **Pathways to death: The co-occurrence of physical and mental health in the last years of life**

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## **Pathways to death: The co-occurrence of physical and mental health in the last years of life**

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### **Abstract**

#### **BACKGROUND**

Physical and mental health are important markers of quality of life. Little is known about how they unfold in tandem in the last years of life.

#### **OBJECTIVE**

We take a life-course perspective to identify typical joint trajectories of functional limitations and depression in the last eight years before death. Our objective is to assess whether there is only a linear association between functional limitations and depression or if we also find groups marked by high and increasing functional limitations but low depression, and vice versa.

#### **METHODS**

Data from 10 waves of the Health and Retirement Study that cover US Americans who died between 2003–2014 are analyzed with sequence, cluster, and multinomial logistic regression methods.

#### **RESULTS**

Results show five typical trajectories of joint functional limitations and depression. Corroborating previous findings, three groups support a linear positive relationship between functional limitations and depression. Beyond previous research, we find two resilient groups of medium and high functional limitations combined with stable low depression. The five groups are highly stratified by social status, gender, marital status, and subjective life expectancy reported at the beginning of the trajectories.

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## **CONCLUSION**

Physical and mental health trajectories at the end of life are not only linearly associated. Medium and high functional limitations go along with a polarized pattern of either stable high or stable low depression.

## **CONTRIBUTION**

The nonlinear relationship between functional limitations and depression in the last years of life represented by the ‘Resilient’ groups of medium and high functional limitations with low depression have gone largely unnoticed in previous research and should be investigated in future studies.

## **1. Introduction**

Next to social disparities in mortality (Hayward, Hummer, and Sasson 2015; Hoffmann 2011; van Raalte et al. 2011; Torssander and Erikson 2010), social differences in health trajectories preceding death are an important marker of social inequality. Research has only relatively recently started to examine longitudinal trajectories of change in physical and mental health at the end of life, usually focusing on only one health dimension (Diegelmann, Schilling, and Wahl 2016; Gill et al. 2010; Wolf 2016). A multidimensional perspective on end-of-life health trajectories is important to assess the variants of ‘successful aging’ and their temporal dynamics in order to give a more complete picture of individual aging experiences (Kok et al. 2015; Rowe and Kahn 1987). To date, the dynamic parallel development of physical and mental health in old age remains relatively unexplored for at least two reasons. First, studies aimed at the description of multidimensional end-of-life health trajectories usually include a relatively large number of health dimensions and rely on growth curve and group-based trajectory models (e.g., Hsu and Jones 2012; Wickrama et al. 2013). This approach provides a useful general overview, but is limited to revealing complex nonlinear associations between specific health dimensions as they unfold over time. Second, studies on the association between physical and mental health limitations in old age tend to focus on a unidirectional impact of one dimension on the other and therefore cannot grasp their joint parallel development over longer periods of time. Findings indeed point to a bidirectional relationship (Mezuk et al. 2013) such that physical limitations may reinforce depression (Chang et al. 2009; Ormel et al. 2002) and depression can trigger physical decline (Lenze et al. 2001; Penninx et al. 1999), albeit there is large heterogeneity in these associations.

This paper takes a time-to-death perspective, well established in the gerontological literature (Diegelmann et al. 2016; Gerstorf et al. 2010; Wolf et al. 2015), to describe

the co-occurrence of functional limitations and depression in the last eight years before death. We ask: First, which typical joint trajectories of functional limitations and depression occur in the last eight years of life (RQ 1)? In particular, is there a linear positive relationship between functional limitations and depression, or do we also find nonlinear interactive groups where high and increasing functional limitations go along with low or decreasing depression, and vice versa? Second, how does the likelihood to experience a typical joint trajectory of functional limitations and depression vary with socioeconomic background (RQ 2)? We complement previous research by applying multichannel sequence analysis that can detect complex nonlinear relationships between physical and mental health as they unfold over longer periods of time. Furthermore, our observation period of eight years before death is longer than in most previous studies and therefore more suitable to capture the initial onset of physical and psychological decline. Identifying interactive nonlinear associations between functional limitations and depression, if they exist, is important to document the heterogeneity of end-of life health trajectories and to identify potential protective factors that keep depression low despite physical health limitations, and vice versa.

## **2. Data**

We use data from 10 waves (1994–2014) of the Health and Retirement Study (HRS, 2016). In 1992, the HRS started as a national biannual panel survey of 51- to 61-year-old Americans and their spouses. Additional study cohorts were included every six years since 1992. The total HRS sample comprises more than 37,000 respondents, of which 12,535 died during the study period. For extracting disability and depression trajectories, we require data on respondents who continuously participated for four waves prior to death. Only 5,746 respondents meet this selection criterion. Given the biannual rhythm of the survey, the persons remaining in the sample died within 24 months after their last interview. Complete and consistent information on disability and depression is only available if the respondents were physically and cognitively able to complete the interviews themselves. Consequently, we exclude 1,822 respondents with proxy interviews (remaining  $N = 3,924$ ). Given few missing values on the covariates (less than 7%), we use a complete case sample of  $N = 3,664$ . The only exception to the list-wise deletion of cases with missing values is an indicator on subjective life expectancy, for which a flag variable indicates missingness, since we would otherwise lose an additional 478 cases (13% of the sample). Findings were substantively robust to multiple imputations of missing values in the trajectories of functional limitations and depression and the covariates. Lacking a well-established and consistent imputation procedure for sequence data that also includes missing values on covariates (Halpin

2016), we only present results on the complete case sample. All data was retrieved from the RAND HRS file (version P), which are cleaned and processed by the RAND Center for the Study of Aging (RAND HRS 2016) with funding from the National Institute on Aging and the Social Security Administration. The measures required for our analyses were available from Waves 2 through 11.

All analyses are weighted using the terminal year weight as suggested by the HRS team (<http://hrsonline.isr.umich.edu/sitedocs/wgthdoc.pdf>). Results are substantively robust without weights. Despite many advantages of the HRS to investigate our research questions, we miss the ‘worst-off’ people who could not complete the questionnaire long before death, and those who did not consistently participate in the last four waves before dying. It is well known that survey data systematically underestimates the progression and severity of health problems due to nonrandom attrition (Wolf 2016; see Jackson, Engelman, and Bandeen-Roche 2017 for detailed information on potential strategies for quantifying the extent of bias). We therefore cannot map the entire heterogeneity in end-of-life health trajectories, and the prevalence of the groups in the following typology should be interpreted with some caution. That said, even our restricted sample reveals considerable and systematic heterogeneity of end-of-life health trajectories and demonstrates the existence of nonlinear interactive patterns of functional limitations and depression in the last years before death. Moreover, selective attrition likely is more problematic for studying variation in severe disability compared to our measure of functional limitations. “Functional limitations are restrictions in performing fundamental physical and mental actions in daily life” (Verbrugge and Jette 1994: 3). Compared to disability, they encompass less severe forms of physical health limitations.

Functional limitations are operationalized as an index of three count scales that are consistent across waves ( $\alpha = 0.72$ ) including the following dimensions and items: 1) difficulty with gross motor skills (e.g., walking one block, walking across the room, climbing one flight of stairs, bathing); 2) difficulty with large muscle skills (e.g., sitting for two hours, getting up from a chair, stooping, kneeling or crouching, pushing or pulling a large object); and 3) difficulty with fine motor skills (e.g., picking up a dime, eating, dressing). Zero indicates none of these difficulties, whereas eleven indicates all of them.

Depression is operationalized according to the Center for Epidemiologic Studies Depression scale (CESD), which comprises the sum of six ‘negative’ minus two ‘positive’ indicators. The negative indicators include whether individuals had the following experiences all or most of the time: depression, restless sleep, or a sense that everything is an effort, that they could not get going, or that they felt alone or sad. The positive indicators are if individuals felt happy or enjoyed life all or most of the time. Zero indicates the presence of none of the negative indicators or positive indicators,

while 8 denotes all negative indicators were experienced much of the time over the week prior to the interview, but none of the positive indicators.

### **3. Methods**

The analysis proceeds in three steps. First, we use multichannel sequence analysis with optimal matching (Gauthier et al. 2010; Pollock 2007) to determine the similarity between multidimensional trajectories of functional limitations and depression. Multichannel sequence analysis classifies holistic longitudinal experiences in terms of interactions between the dimensions considered, in our case functional limitations and depression (Pollock 2007: 176). Two multidimensional trajectories are considered similar if they are similar in both the physical and mental health dimension. Optimal matching calculates the distance between two sequences as the minimum possible ‘cost’ of turning one sequence into another based on three transformation operations that are assigned specific costs. We align the two-dimensional trajectories with substitution costs specified as the absolute distance between the count scales of functional limitations and depression, respectively. For instance, substituting 1 on the depression scale with 7 comes at the cost of 6 (7–1). The cost specification thus corresponds to the count data nature of our measurements. The alignment yields a distance matrix that summarizes distances between each pair of the two-dimensional health trajectories.

Second, we apply Partitioning around the Medoid cluster analysis on the distance matrix to identify groups of typical joint physical and mental health trajectories. Several cluster cutoff criteria unanimously support five clusters as the best grouping (Studer 2013).

Third, to assess the likelihood of experiencing one of the five end-of-life health trajectories, we use a multinomial logistic regression including predictors on standard sociodemographics (e.g., gender, year of birth, race, education, economic well-being, marital status) and subjective life expectancy (descriptive information in Table 1). They all were measured at the beginning of the trajectories to ensure temporal precedence with two exceptions: 1) Missing information on subjective life expectancy at the first observation was replaced with information from the second observation; and 2) we generated a variable indicating the transition to widowhood during the last eight years before death. Wealth is constructed as a relative measure using quartiles of the distribution compared to an individual’s peers in terms of gender, household size, and age using the entire HRS sample as the benchmark. Subjective life expectancy contrasts self-reported life expectancy with the statistically calculated life expectancy from the annual life tables of the Vital Statistics. It is a relative measure in quartiles compared to individuals’ peers in terms of gender and age. The bottom 25%, categorized as



‘pessimists,’ tend to assume that they will live shorter than indicated by the Vital Statistics and are more negative about their life expectancy than their peers. The middle 50% are coded as ‘realists’ and the top 25% as ‘optimists.’ All sequence and cluster analyses were conducted using the TraMineR (Gabadinho et al. 2011) and Weighted Cluster (Studer 2013) packages in R (Version 3.4.3). Regression analyses and marginal effects were estimated in Stata (Version 15.1) using commands from the SPost13 package (Long and Freese 2014).

**Table 1: Descriptive information by cluster membership (N = 3664)**

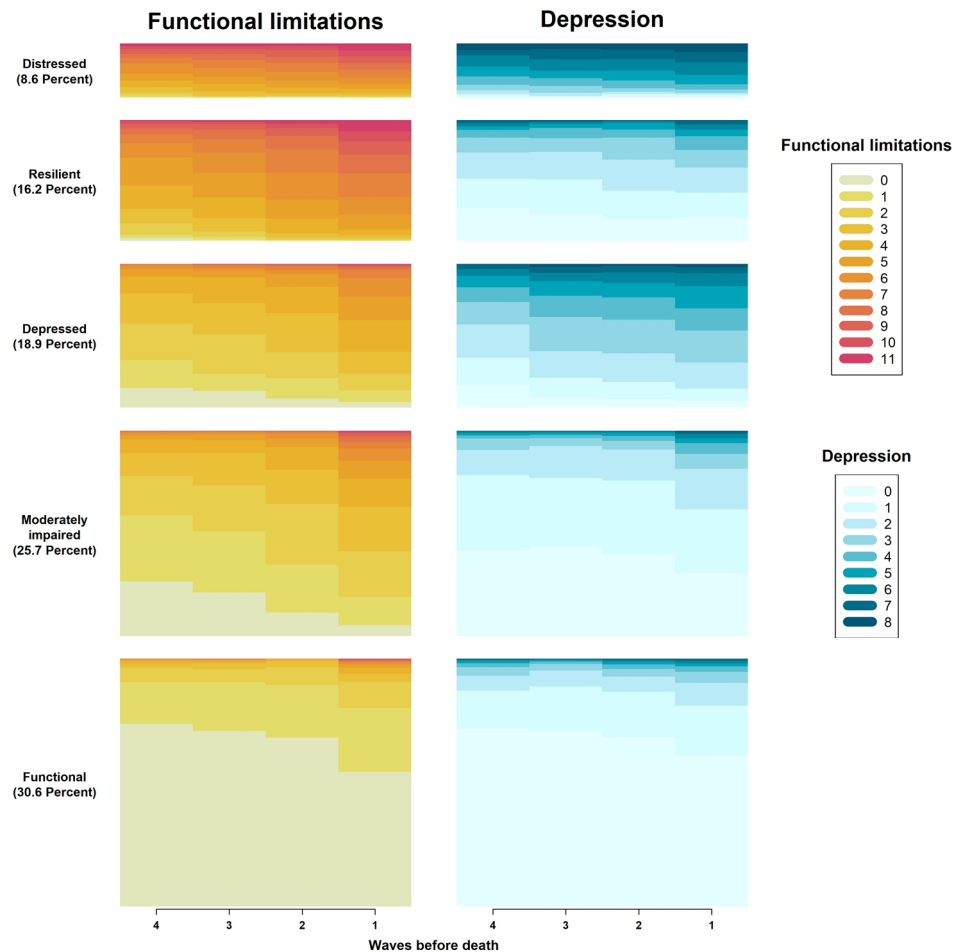
	Pathway to death					
	Functional	Moderately impaired	Depressed	Resilient	Distressed	Total
<b>Birth year</b>	1930.61 (10.05)	1928.48 (10.12)	1928.50 (10.66)	1927.73 (11.12)	1932.17 (10.87)	1929.23 (10.52)
<b>Gender – male</b>	0.63	0.55	0.38	0.36	0.37	0.49
<b>Race – black</b>	0.07	0.07	0.10	0.11	0.15	0.09
<b>Age at death</b>	77.17 (9.98)	79.47 (9.81)	79.12 (10.36)	80.81 (10.70)	75.87 (10.62)	78.72 (10.28)
<b>Months to death (after last interview)</b>	13.03 (6.50)	12.15 (6.55)	12.46 (6.57)	12.40 (6.81)	12.13 (6.59)	12.48 (6.59)
<b>Education – some college</b>	0.44	0.38	0.26	0.38	0.21	0.36
<b>Marital status</b>						
married	0.67	0.62	0.52	0.52	0.47	0.59
sep./div./never married	0.13	0.13	0.16	0.15	0.23	0.15
widowed	0.20	0.25	0.32	0.33	0.31	0.27
<b>Transition to widowhood</b>	0.10	0.13	0.16	0.13	0.15	0.13
<b>Medicaid recipient</b>	0.04	0.03	0.08	0.11	0.23	0.07
<b>Total wealth</b>						
1. quartile	0.16	0.21	0.29	0.29	0.47	0.25
2. quartile	0.24	0.28	0.26	0.24	0.27	0.26
3. quartile	0.27	0.26	0.24	0.25	0.16	0.25
4. quartile	0.33	0.25	0.21	0.22	0.11	0.25
<b>Life expectancy</b>						
pessimist	0.18	0.26	0.34	0.34	0.50	0.29
realist	0.49	0.41	0.39	0.33	0.31	0.41
optimist	0.24	0.22	0.14	0.15	0.09	0.19
missing	0.09	0.11	0.13	0.18	0.11	0.12
<b>Disability</b>						
first observation	0.42 (0.88)	1.57 (1.50)	2.29 (1.56)	4.86 (2.20)	5.87 (2.62)	2.32 (2.44)
last observation	0.94 (1.58)	3.26 (2.12)	4.04 (2.01)	7.26 (2.27)	7.36 (2.51)	3.82 (3.06)
<b>Depression</b>						
first observation	0.56 (1.18)	0.97 (1.17)	2.40 (1.85)	1.83 (1.79)	4.96 (2.03)	1.62 (1.95)
last observation	0.81 (1.40)	1.51 (1.58)	3.51 (1.88)	2.35 (1.95)	5.50 (1.97)	2.19 (2.19)
<b>Relative frequency</b>	0.26	0.31	0.19	0.16	0.09	1

Note: Mean values and standard deviations (in parentheses).

## 4. Results

Figure 1 visualizes the five clusters as state distribution plots. Functional limitations are shown on the left and depression on the right. The relative size of each group corresponds to the size in the sample. We name the five groups: 1) ‘Functional (26%),’ 2) ‘Moderately impaired (31%),’ 3) ‘Depressed (19%),’ 4) ‘Resilient (16%),’ and 5) ‘Distressed (9%).’

**Figure 1: State distribution plots by cluster membership (view in color)**



The 'Distressed' group (top of Figure 1) combines stable high depression and severe functional limitations throughout the last eight years before death. In contrast, the 'Functional' cluster at the bottom of Figure 1 shows very low, albeit gradually increasing limitations combined with low depression. Cluster 3 'Depressed' is an intermediary group with both functional limitations and depression values between these two extremes but notable depression levels despite only physical limitations (see averages in Table 1). Clusters 1, 3, and 5 are in line with a linear and mutually reinforcing association between physical and mental health in the last years of life (Chang et al. 2009; Hsu and Jones 2012; Kok et al. 2015). In contrast, the 'Resilient' and 'Moderately impaired' groups both show stable low depression trajectories combined with very high and medium functional limitations, thus supporting a nonlinear interactive relationship between physical and mental health at the end of life for part of the population (RQ 1). Particularly, the 'Resilient' group with very low depression despite severe functional limitations has gone largely unnoticed in previous research. Overall, the trajectories highlight remarkable stability over time for the 'Distressed' and 'Resilient' groups and a slight increase in functional limitations and depression for the 'Depressed,' 'Moderately impaired,' and 'Functional' groups particularly in the final year before death (Figure 1).

To address RQ 2 we predict cluster membership using multinomial logistic regression. Table 2 shows the resulting average marginal effects that indicate the average change in percentage points to be in a given cluster in response to a one unit or one standard deviation change in the independent variables all else equal. Results support that traditional markers of social stratification (e.g., gender, race, education, wealth, receipt of welfare support) are associated with end-of-life health trajectories. In line with previous research (Doblhammer and Hoffmann 2010), men have a higher probability to be in the 'Functional' (10.2) and 'Moderately impaired' (5.6) groups. In contrast, their probability to experience the 'Depressed,' 'Resilient' or 'Distressed' trajectories is lower compared to women by 6.0, 7.7, and 2.1 percentage points, respectively (Table 2). Unlike in the bivariate distributions (Table 1), we find no differences in the likelihood to experience a given end-of-life health trajectory between black and white older Americans in the multivariate models. In fact, race differences are fully accounted for by additional covariates, whereas gender differences remain significant and sizeable (AMEs in Table 2).

Compared to their peers with no college education, respondents with some college education are more likely to experience the 'Functional' (2.6) and the 'Resilient' (4.8) clusters but are less likely to sort into the 'Distressed' (2.8) or 'Depressed' (5.6) groups. Wealth is even more predictive of group membership. Being in the top wealthiest quartile compared to the lowest quartile increases the probability of being in the

‘Functional’ group by 15.7 percentage points while lowering chances to enter the ‘Depressed’ (5.3) or ‘Distressed’ clusters (7.9).

**Table 2: Average marginal effects based on the multinomial logistic regression (AMEs)**

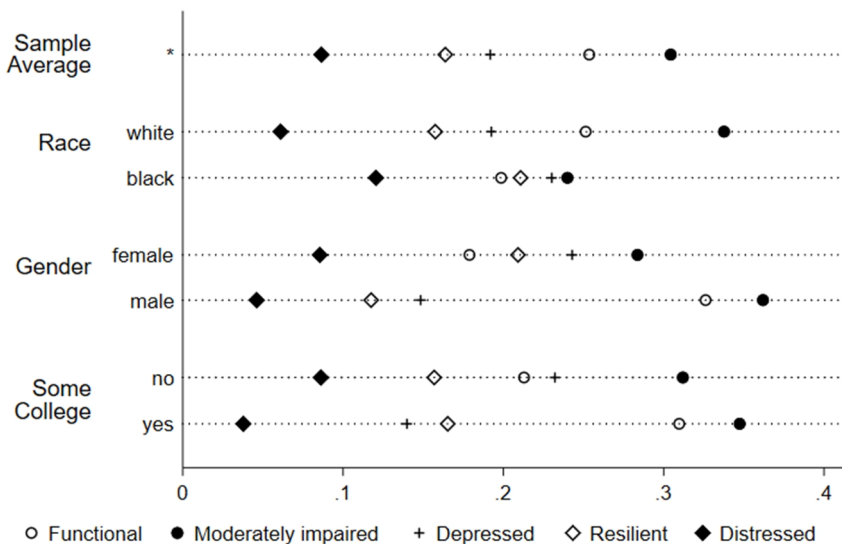
	Pathway to death									
	Functional		Moderately impaired		Depressed	Resilient	Distressed			
<b>Months to death</b>										
change by one SD	0.031	***	−0.015	*	0.000	−0.008	−0.007	+		
<b>Birth year</b>										
change by one SD	−0.031	+	−0.008		−0.042	**	0.069	**	0.012	
<b>Gender</b>										
male vs female	0.102	***	0.056	***	−0.060	***	−0.077	***	−0.021	*
<b>Race</b>										
black vs. white	0.010		−0.039		0.000		0.034		−0.006	
<b>Age at death</b>										
change by one SD	−0.069	***	0.012		−0.042	**	0.109	***	−0.010	
<b>Education – some college</b>										
yes vs no	0.026	+	0.013		−0.059	***	0.048	***	−0.028	**
<b>Marital status (ref.: married)</b>										
sep/div/never married	−0.053	**	−0.022		0.035	+	0.004		0.035	**
widowed	−0.053	**	−0.028		0.036	*	−0.002		0.046	***
<b>Transition to widowhood</b>										
yes vs. no	−0.048	*	−0.008		0.046	*	−0.016		0.026	+
<b>Medicaid recipient</b>										
yes vs. no	−0.035		−0.129	***	−0.008		0.078	**	0.094	***
<b>Total wealth (ref.: lowest quartile)</b>										
2. quartile	0.072	***	0.049	*	−0.032	+	−0.044	*	−0.045	***
3. quartile	0.106	***	0.026		−0.035	+	−0.029		−0.068	***
4. quartile	0.157	***	0.015		−0.040	+	−0.053	**	−0.079	***
<b>Subjective life expectancy (ref.: pessimist)</b>										
realist	0.138	***	0.018		−0.032	*	−0.064	***	−0.060	***
optimist	0.157	***	0.072	**	−0.074	***	−0.066	***	−0.089	***
missing	0.099	***	−0.025		−0.028		−0.011		−0.035	+

Separated, divorced, never married, and widowed individuals are significantly less likely to experience a ‘Functional’ trajectory and more likely to be in the ‘Depressed’ and ‘Distressed’ groups compared to their married peers. A polarization of end-of-life health trajectories between married and unmarried older adults is further corroborated by findings for entering widowhood in the observation period (experienced by 13%). Losing a spouse decreases the likelihood for the ‘Functional’ cluster (4.8) while increasing the risk of experiencing the ‘Depressed’ trajectory by 4.6 percentage points. Finally, subjective life expectancy is highly predictive of end-of-life health trajectories. Compared to pessimists, optimists have a notably higher probability to be in the ‘Functional’ and ‘Moderately impaired’ groups (15.7 and 7.2). Optimists’ probabilities

to experience the remaining groups are reduced by 7.4 ('Depressed'), 6.6 ('Resilient'), and 8.9 percentage points ('Distressed').

The average marginal effects (AMEs) in Table 2 report the isolated effect of a change in an independent variable holding all other variables constant. Predictions of cluster membership by race, gender, and education that hold all other independent variables at their group specific means (MEMs) give a more intuitive interpretation (Figure 2). MEMs reflect the probability to be in each cluster for an 'average women' or 'average black' older adult. They complement the AMEs in Table 2 by considering all measured group differences simultaneously. While the AME for men to experience the 'Functional' trajectory is 10 percentage points (Table 2), the MEM amounts to 15 percentage points (33% for men vs 18% for women in Figure 2) because in our study cohorts men are on average higher educated and wealthier than women. Similarly the MEMs in Figure 2 point to notable group differences for education and race. While racial differences disappear when controlling for other variables (AMEs in Table 2), the MEMs highlight compositional differences between black and white Americans – for instance in terms of education – which let them experience very different pathways to death.

**Figure 2: Adjusted predictions (percentage points) at group specific means (MEMs)**



## 5. Conclusions

This paper explored complex nonlinear associations in the co-occurrence of physical and mental health in the last eight years before death. Results highlight five distinct groups of joint trajectories of functional limitations and depression at the end of life in the United States. Next to three groups that support a linear positive relationship between disability and depression, we find two sizeable groups (31% and 16%) that have gone largely unnoticed in previous research: the ‘Moderately impaired’ and ‘Resilient’ clusters. They have almost identical stable medium and high functional limitation trajectories as the ‘Depressed’ and ‘Distressed’ groups but differ with highly stable low depression trajectories. Findings thereby support a nonlinear interactive pattern between physical and mental health in the medium and high range of functional limitations. The ‘Functional’ and ‘Moderately impaired’ groups highlight heterogeneity within relatively high functioning aging processes and could be considered different variants of ‘successful aging’ (Kok et al. 2015). In addition, the ‘Resilient’ group could be considered as successful aging in terms of psychological wellbeing despite severe functional limitations.

In line with previous research, women suffer more (Doblhammer and Hoffmann 2010; van Houwelingen et al. 2014; Smith et al. 2013), and wealth (Torres et al. 2016) and education (Thorpe et al. 2011) protect against the most strenuous end-of-life health trajectories (see also Wolf 2016). Predictors for the two interactive groups the ‘Moderately impaired’ and ‘Resilient’ operate in very different ways. Respondents who are male, in the second wealth quantile, do not receive Medicaid, and are optimistic about their life expectancy are more likely to experience a ‘Moderately impaired’ trajectory. In contrast, respondents who are female, belong to younger birth cohorts, died at higher ages, are college educated, receive Medicaid, and are rather pessimistic about their life expectancy are most likely to be in the ‘resilient’ group. Cohort and age-specific factors possibly play a role for their ability to maintain high mental health despite severe long-term disability. Moreover, our results support remarkable stability in functional limitations (for similar results on disability see Gill et al. 2013) and depression over the last eight years of life with only slight increases in the final year before death that are in line with a ‘compression of morbidity.’

Taken together our findings have two important implications for future research and policy interventions. First, the results underline the heterogeneity and malleability of multidimensional aging processes. More energy should be directed at identifying and fostering protective factors that enable individuals to maintain low levels of depression despite physical health limitations, including genetic and epigenetic factors, health behaviors, and environmental and socio-economic conditions. Second, the relatively high prevalence of the early onset of functional limitations and depression taking place

many years before death for a large share of our sample necessitates a longer-term life-course perspective on end-of-life health trajectories. If cumulative disadvantage starting early in life sets individuals on trajectories of high lifetime morbidity and mortality, social policies to enhance ‘successful aging’ have to target preventive measures and early life stages (Case and Deaton 2017; Schafer, Ferraro, and Mustillo 2011).

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